DOCUMENT RESUME

ED 276 910 CG 019 525

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TITLE Widows and Widowers of Dementia Victims: Their Survival after Spouses' Death.
PUB DATE Nov 86
NOTE 19p.; Paper presented at the Annual Scientific Meeting of the Gerontological Society (39th, Chicago, IL, November 19-23, 1986).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Coping; *Death; *Grief; Mental Disorders; Middle Aged Adults; Older Adults; *Social Support Groups; Spouses; Stress Variables; *Widowed
IDENTIFIERS *Alzheimers Disease; *Caregivers

ABSTRACT

The grieving process for widows and widowers of Alzheimer's victims is a uniquely complicated and painful one. To examine this issue, an exploratory study was conducted of 27 females and 13 males whose spouses, all dementia victims, had died between 3 months and 3 years prior to the study. In addition to these 40 interviews, an extensive literature review was done on caregivers of dementia victims and on coping strategies of people under stress. Eighty questionnaires completed by relatives of deceased Alzheimer's victims from a previous study (Coons et al., 1983) were also reviewed. Although an analysis of these data suggests that coping mechanisms for survival seem as infinite as the number of respondents, a few key issues did emerge: (1) transition into a nursing home seemed to be the most consistent trauma for caregivers; (2) experiences with nursing home placement varied from the extreme positive to the extreme negative; and (3) respondents reported that their caregiving experience made them stronger (N=25), more accepting (N=15), bitter (N=9), or weaker (N=10). Some respondents reported the help they received by remaining in support groups after the death of their spouse. Respondents felt that caregiver support groups should incorporate practical issues, caregiver needs, and help with nursing home placement into their programs. (NB)

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Widows and Widowers of Dementia Victims:

Their Survival After Spouses' Death*

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*We are most grateful to the following interviewers for their invaluable help:

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ABSTRACT

The grieving process for widows and widowers of Alzheimer's victims is a uniquely complicated and painful one. Based on an analysis of literature about grieving and loss, and using clinical illustrations from our work with these survivors, this paper points to key issues and implications for the design of support groups.

Widows and Widowers of Dementia Victims:

Their Survival After Spouses' Death

Alzheimers

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Betty Morgan (1984)[1]
3051 Rio Dosa Dr.
Lexington, KY 40509

Pronounce it Alzheimer's

Color it grey.

Diagnose it only at death.

Do brain scans

To show shrinkage,

Diffuse atrophy.

See neurons all tangled,

Plagues intertwined,

Absence of acetylcholine.

Call it dementia, madness

A disease

That kills not one, but two.

---

[1]Morgan, Betty. (1984). Alzheimer's. Generations, IX, 2, 55.

Rationale for Project

Research and common sense observations show that future problems related to serious emotional stress tend to develop when grief is intense, prolonged, and largely unresolved. This is particularly true when the grief and loss have been long, complicated, and associated with negative feelings, as is often the case when dealing with the dementias.

Dementias create dreadful burdens for caregivers. The grief tends to be compounded with anger and guilt, and our culture usually does not recognize that the caregivers are grieving. There are no rituals or opportunities to "normally" grieve during this long, devastating illness. For these reasons we wonder if caregivers, especially spouses, are often prone to future emotional troubles after the death of their partner.

Dr. C. Murray Parkes and R.S. Weiss (1983), leading authorities on bereavement reactions, report that many physical symptoms in family members increase by 50 percent following a death in the family, and that following the death of a spouse seven times the normal amount of women and four times as many men enter psychiatric care. Dr. Jerome Frederick (no date), a biophysiologist, writes:

> There seems to be little doubt that people undergoing unresolved grief, who at one time had arrested T.B., during . . . bereavement redeveloped active T.B. (p. 8).

Physicians now speak of grief as the hidden illness, and think it may account for many of the physical symptoms they see in their daily practice. There is a higher than average mortality rate for widowers in the first year of their bereavement.

When Warden (1982) did his studies on anticipating grief, which is what spouses of dementia victims go through, he felt that data were inconclusive as to whether anticipation was helpful or not. For many, he said, anticipatory grief increased anxiety and also increased personal death awareness in the care-

giver. So even the often assumed notion that anticipatory grief is helpful comes under question.

Silver and Wortman (1980) did an extensive literature review on coping strategies of people under severe, prolonged stress, and came to the following conclusion:

> Clearly, the evidence reviewed suggests that a simple expectation of acceptance or recovery from a serious life crisis is unwarranted for a large minority of people. Most studies find significant levels of distress or disorganization after a year, and those that have continued to follow their sample for a longer period of time have not typically found substantial improvement. . . . There are relatively few studies that have documented reactions to life crises several years after the event has occurred. Nevertheless, there is a clear suggestion from the available evidence that for many people acceptance or recovery is not apparent despite the passage of a long period of time.
>
> In conclusion, it is clear that prevailing notions of recovery need to be reconsidered. There is evidence that a substantial minority of individuals exhibit distress for a much longer period of time than would be commonly expected. There are also a number of indications that people continually re-experience the crises for the rest of their lives (pp. 307-308).

Our rationale for this project, then, is based on the notion that widows and widowers of dementia victims, because their bereavement process in unique, may be having a rough survival period, about which we know very little. By talking with them, we hoped to learn more. We specifically hoped to learn how support groups for caregivers might better address the present and future needs of the members.

Hospice care has long recognized the need for after-care with the bereaved, and as a national policy builds this care in for a minimum of one year after the death. We are suggesting the same model for spouses of dementia victims. Our hypothesis is that future problems could be ameliorated by counseling before or soon after the death of the spouse.

Introduction

Our exploratory study was based on 40 two-hour interviews with widows and widowers of dementia victims (See Appendix A). Our subjects were from Wisconsin and Michigan, ranged in ages from 50 to 93, were all white, and were largely from Alzheimer's Disease and Related Disorders Association (ADRDA) support groups. Our sample consisted of 27 females and 13 males whose spouses had died between 3 months and 3 years prior to the interview.

Our sample is biased: people who belong to ADRDA and other support groups are probably better off in many ways than those who do not belong; our people were all white, largely middle class, and from the midwest. So while our sample is far from perfect, the responses of the interviewees provide a beginning for understanding the difficulties and emotions experienced during this vulnerable period. We are aware that 3 months after death looks very different from 3 years after death, as do all the many stages in-between. We were asking for their expertise and advice: "What has this survival been like for you? What advice do you have for us, for today's caregivers and support groups?"

In addition to our 40 interviews, we did an extensive literature review on caregivers of dementia victims, and on coping strategies of people under stress. We also reviewed 80 questionnaires completed by relatives of deceased Alzheimer victims from a previous study by Coons et al. (1983). (See Appendix B). A number of the questions from this questionnaire were directly related to the present study, in that the 1983 study dealt with the subjective experiences of families dealing with Alzheimer's Disease.

From the moment of inception we had two main goals in mind: 1) What could we learn from our study to incorporate into the running of support groups that might prove helpful to caregivers, both in their present and future lives? And, 2) Are there any clinical or policy implications in our findings?

LITERATURE REVIEW

There has been much literature in recent years about family caregivers of dementia victims as they care for their relative. There are also bodies of literature on grieving, stress, and recovery from loss. What we have not been able to find is any literature dealing specifically with the survival of caregivers after the death of their spouse from dementia.

We have attempted to draw from some of the literature about grieving, stress, and loss, that which seems relevant to our present study of widows and widowers. In our study we present a tentative exploration of a recovery process for spouses of dementia victims.

Sudden vs. Expected Death

There is a commonly held view that sudden death produces more disturbed survivors than does gradual, expected death. In a study by Fulton and Cottesman (1980) of older men and women, there was a negative correlation between length of illness and the emotional response of the survivors. The longer the terminal illness, the more likely there was for a poor outcome for the surviving spouse. Rando (1984) comes to the same conclusion.

> Despite the importance of a period of preparation prior to death, there is some evidence that too long a period of forewarning can also predispose grievers to poorer bereavement outcomes (p. 52).

Rando writes that the longer the illness, the angrier caretakers become, and consequently the more atypical grief responses they evidence after the death. A long drawn out illness leads the caretaker to decathect from the patient, which often causes guilt feelings.

A 1984 study done by the Committee for the Study of Health Consequences of the Stress of Bereavement (Osterweis, Solomon, and Green), comes to a similar conclusion.

> But if life is prolonged for someone who is unconscious or in pain, or whose personality and mental function have been dramatically altered by the illness or treatment, then such extensions of life may make the anticipation of death and the subsequent bereavement more difficult for survivors (p. 4).

Simos (1979) points out that a long, drawn out illness can cause depletion in the caregiver.

> In depression, narcissisticly important goals are still maintained; in depletion they are altered, if not altogether abandoned (p. 241).

It is not clear what we are seeing when caregivers express resignation and apathy. Is it depression, or true depletion? What seems like resignation and acceptance, Simos writes, may in reality be a defense mechanism against overwhelming threat and loss.

Depletion, apathy, resignation, and helplessness were all dominant themes that showed up in connection with prolonged grieving, both in the literature and in our interviews. Most studies on bereavement focus on the first year. Anticipatory grieving, particularly when it is prolonged, deserves more rigorous study.

Bowling and Cartwright (1982) studied a random sample of 361 elderly widowed people in England. For these people practical problems caused the most serious adjustment difficulties. Those most frequently listed were: adaptation to living alone, coping with new household tasks, and adjusting to less money.

Complicated Grief

Both Parkes (1983) and Warden (1982) found that spouses who were angriest following the death of their partner also experienced the highest degree of social isolation. Warden discusses failure to grieve as a predictor of future difficulties. Much of this failure to grieve is traced to the absence of social sanctions for expressing one's negative feelings. He lists three social conditions which may give rise to complicated grief reactions:

1. When the loss is socially unspeakable, as many in our society feel dementia is.
2. When the loss is socially negated. This is true with dementias, both in our lack of medicare and medicaid services, and in our social isolation of victims and their caregivers.
3. When there is an absence of social support networks.

In addition to the absence of social sanctions to grieve, Warden mentions several other reasons why people might fail to grieve:

1. Relationship factors, especially if they were highly ambivalent or highly dependent.
2. Circumstantial factors, especially poverty.
3. Historical factors, especially if a person has had a history of previous losses and separations or a history of depression.
4. And last, but in our opinion an important factor, people are different -- with different capacities for tolerating stress.

He goes on to list grief reactions that he considers complicated and in need of resolution: chronic, delayed, exaggerated, and masked. An atmosphere of support, compassion, and acceptance for expressing negative thoughts and feelings, he feels, will help resolve some of the grief.

Weisman (1984) makes this same point as the central theme in his book The Coping Capacity. He believes that life is full of unpredictable, uncontrollable events that upset us. The notion that one can control and direct one's life is irrational. The best people can do is learn to cope well.

> Many human problems have no discernable solutions. Our morale and self-esteem are exposed to a variety of erosions and explosions, and distress is almost a natural state of being (p. 63).

> We can cope, and learn to cope better. We cannot eliminate problems and certainly cannot eradicate death (p. 30).

Institutionalization

Since most of our interviewees expressed very high levels of stress around the issue of institutionalizing their husband or wife, we were interested in literature on nursing home decisions.

Study after study suggest that caregivers resort to nursing home placement only after they have totally exhausted their own physical and emotional resources (Crossman, et al. 1981). The decision to place a relative in a nursing home is a very difficult one for many caregivers. Informants say that they make the decision when they just can no longer endure the situation. Either the caregiver realizes that he or she is totally exhausted and out of control, and no longer able to manage, or else someone who is close to the caregiver advises that the time has come. Since dementia patients' physical needs often escalate, it becomes more and more difficult to care for them without the professional help that a nursing home provides.

Powell and Courtice (1983) say that institutionalizing a dementia victim forces the spouse to face her own aging and even the chances of getting Alzheimer's disease herself. These thoughts are sometimes too much to bear.

As mentioned in the beginning of this literature review, we have been able to find only related writings, not literature specifically on widows and widowers of dementia victims. One of the most meaningful articles was written in the context of why adult children have so much guilt and difficulties around nursing home placement (Brody, 1985). Although we are concerned about spouses, what Brody has to say seems most relevant. She hypothesizes that the disparity between the standards and expectations of devotion we think we should feel, and the unavoidable mixed and/or negative feelings we do have, leads to guilt. Most people carry a fantasy that they should somehow do more for their loved one. Placing someone in a nursing home is experienced "as the ultimate failure to

care." This was a theme we found repeatedly as our interviewees expressed trauma over nursing home placement.

DISCUSSION AND IMPLICATIONS

People Are Different

Whether it is death and dying, successful sex, coping with life's many stresses, or baking zucchini bread -- it seems that what we all want is a recipe, a neat package of stages or skills that says this is how it is. With the exception of zucchini bread, this does not seem to be the case. And so it is with our survival study of widows and widowers of dementia victims. We looked for patterns of coping or predictable stages of recovery from the caregiving experience. In part, we wanted to find a package of answers that would enable us to say to existing groups of caregivers: here is what is apt to happen and this is what you can do to best prepare yourselves.

Warden (1982) suggests a nine-step therapeutic procedure (pp. 67-73):

1. Rule out physical disease. Since grieving people often experience physical symptoms of stress, it is important to rule out physical disease behind the symptom, if at all possible.
2. Set up a contract of how you will work together to re-explore his or her relationships with the person involved in the loss. Relationships are explored only if they affect the response to the immediate bereavement.
3. Revive memories of the deceased, particularly about positive experiences, to help the patient later on if he or she is experiencing some of the more negative effects. This provides some balance and enables the patient to face some of the negative areas.
4. Assess which grief tasks are not completed, and try to work on those in hopes that the patient will be emancipated from a dysfunctional

attachment to the deceased, and thus be free to move on to other relationships and activities.

5. Deal with affect (or lack thereof) stimulated by memories, particularly the more ambivalent feelings. The goal here is acceptance of all feelings, positive, negative, and mixed. Guilt is often an area that needs a lot of attention and "working through."
6. Explore linking objects, that is, symbolic objects that the survivor keeps to provide a way of maintaining a relationship with the deceased. Understanding the meaning behind these objects, other than as keepsakes, is often very important.
7. Acknowledge the finality of the loss. Some people hang on to the notion that somehow the person will come back in one form or another, and this keeps them from moving on with their lives.
8. Deal with the fantasy of ending grieving, or what they would lose in giving up their grief. This, says Warden, is a simple procedure, but one that is often helpful.
9. Help the patient say a final goodbye. Warden believes that when the unfinished business is completed the patient will know he or she is ready.

Although some of the procedures may seem simplistic and a means of providing the counselor with "neat packages," they touch upon sensitive and difficult areas that face those who are grieving and must be dealt with by counselors.

Osterweis et al. (1984) also mention lack of social support and ambivalence in marital relationships as predictors of poor bereavement outcomes. They describe a bereavement intervention program in which the goals centered around change, not "recovery."

> It was discovered in talking to widows that they never 'recovered' in the sense of returning to all prebereavement

> baselines, but that a successful outcome depended upon their ability to adapt and alter their images and roles to fit their new status (p. 267).

In other words, the most fundamental need for survival was learning how to cope and change.

In re-reading the quantity of subjective interviews before us, perhaps all that can be said for sure is that the coping mechanisms for survival seem as infinite as the number of respondents. Before abandoning the whole project as an exercise in futility, it occurred to us that perhaps this is what we have found and should say -- as obvious as it seems -- that people are very different. The clinical implication of this is: do not make assumptions about how it ought to be -- just listen carefully and try to be helpful. As one interviewee said in response to our asking him if he had advice for families on how to cope: "I think it is impossible to generalize, since each case is so different."

A few key issues did emerge. Transition into a nursing home seemed to be the most consistent trauma for caregivers. It was a decision often made out of desperation. Responses about placement ranged all the way from "I'd never place him in a home, no matter what," to "A good nursing home is the only solution. Don't try to be 'superfamily.'"

Experiences with nursing home placement also varied from the extreme positive to the most negative. On the negative side the most often expressed complaints were: The nursing home was understaffed; the workers did not know enough about dementias; patients were over-drugged; and there was not enough for the patient to do. On the positive side: "Church nursing homes are the best," good care was given to the patient, and staff was pleasant to family members.

When we asked spouses: "How has this whole experience affected your development as a person?", we again got responses that varied from the most positive

("It made me stronger; increased my faith in God"), to the very negative ("It made me very bitter; weaker; nervous"). For some it seemed as if the martyr role was the only possible reward left.

A number of people had combined and mixed feelings on the subject, and expressed their reactions to the question in a number of ways. In one form or another 25 of our sample of 40 said the experience made them "stronger"; 15 said it made them "more accepting"; 9 said it made them "bitter"; and 10 used the word "weaker."

For those spouses who remained in support groups after the death of their victim, there were three gains that were frequently mentioned: It was meaningful for them to try and help others, they were interested in information about dementias, and there was still the comfort of feeling understood by others in the group.

A central question we were interested in is what advice, if any, they had for caregivers, to help them with their adjustment. That is, given what they had been through, did they have words of wisdom for people to prepare themselves for life after the death of their spouse?

Their advice reconfirms the concept that people are different, and we cannot find neat packages in which to frame this process. Some people took a rather passive stance and advised others: "Be accepting, it is God's will, take one day at a time, be patient." Others had an eye to future adjustment, and warned: "Family members have rights, too, and must not give all of themselves for the 'cause'"; "be good to the patient, because you will suffer regrets and guilt if you don't"; "try not to rage because it will only make you feel guilty later on"; "don't be proud -- ask for help"; "continue to visit in the nursing home so you don't feel regrets afterwards"; "stay tender and loving"; "get support to alleviate the guilt around nursing home placement"; "be honest with yourself"; "join a support group and take care of yourself."

Some people stressed practical advice: "Be sure to get control of property and other finances; get legal issues taken care of"; "education about dementias in all its stages is most important; support groups are a must"; and "specify to the doctors not to attach life-support equipment towards the end."

And still others found advice giving beyond them: "I don't know; it was such a nightmare"; "I've asked my daughter to shoot me if I get it"; or, "I just didn't want to lose him, no matter what." One caregiver put it succinctly: "You can't give advice. It depends on whether you place your own life and happiness foremost, or your victim's." "Advice, I really don't know. All I know for sure is that it was very sad and hard on me to see her deteriorate that way." One person summarized this question beautifully: "Each family, and more specifically each family member, has a wide variety of coping and tolerance levels. Therefore, I find it difficult to presume that I could advise others based on my own experience. I don't advise others, I just listen carefully and assure them I understand what they are going through." Sage advice for all of us!

Another issue that came up frequently was one of genetic concern, either for their children or themselves. This is a particularly difficult issue, because we have no answers beyond statistical probabilities. But we must be aware of the fact that many people are worried about genetic factors, and provide an opportunity for discussion. Unspoken fears are probably worse than those that can be discussed openly.

In many ways our central question remains: Is dementia bereavement different from and more difficult than other bereavement situations? Our hypothesis is that it is. Because dementias destroy the brain, the very essence of a person, we wonder if the problems and stresses for spouses are not more complicated than in other terminal diseases.

Summary

The most significant finding from our exploratory study with widows and widowers of dementia victims is that you cannot make generalizations about their recovery process. It follows, then, that the most important implication for practice is to sharpen our skills at listening very carefully to what we are being told. On some level, this is a self-evident statement. But sometimes we all need to be reminded of it, as we search for neat packages of explanations for human behavior -- in order to make us feel more secure in our work.

Our interviewees did spell out the helpfulness of support groups for caregivers, both during the long course of the illness, and after the death of their spouse. Most people benefit from remaining in a support group, or from getting some kind of supportive counseling, during the recovery period after the death of their spouse. It is our recommendation that this after-care service be routinely offered. To lose a spouse from dementia may be one of the most difficult and complicated bereavement processes there is.

Our sample stressed three main areas they felt should be incorporated into caregiver support groups.

1. Practical issues, i.e., legality and financial concerns; letting the doctor know whether or not the family wishes life supports to be used at the end; knowing as much as possible about the dementias and their course, from beginning to end.
2. Caregiver needs, both emotional and practical.
3. Help with nursing home placement: both the practical and financial side, and the emotional one of making that decision and then living with it. People seem to feel the whole gamut of responses from relief to burdensome guilt.

According to Morycz social support is the most important variable in reducing stress for caregivers, so it stands to reason that support groups are of paramount importance.

> . . . dementia will be the most common cause of institutionalization in this country. It therefore will be crucial for health care providers and social policymakers to be better informed about the nature of social costs of family support to the aged with mental impairment (Morycz, 1985, p. 356).

Last, but surely not least, we were very touched by the eagerness of so many caregivers to give of themselves. They gave to their spouses and were eager to help others in support groups. Their willingness to participate in this study reflects a wish to offer their valuable help and advice to present and future caregivers.

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